

Contents lists available at ScienceDirect

Seizure

journal homepage: www.elsevier.com/locate/yseiz

A comparative study of health related quality of life, psychological well-being, impact of illness and stigma in epilepsy and migraine

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ARTICLE INFO

Article history:

Received 7 January 2011

Received in revised form 23 June 2011

Accepted 25 June 2011

Keywords:

HRQOL

Depression

Stigma

Disclosure

Limitation

Impact of illness

Spiritual healing methods

ABSTRACT

This study aimed to show the difference of epilepsy from another chronic neurological disorder with episodic manifestations (CDEM): migraine. Seventy persons with epilepsy (PWE), 56 persons with migraine (PWM) and 45 healthy control participants (HCs) were included. The groups were compared in terms of demographics, quality of life, depression and self-esteem. The PWE and PWM were also compared with regard to stigma, impact of the illness, disclosure, application of spiritual/traditional healing methods, limitations, most affected life areas, and restrictions. Results showed that the PWM had lower quality of life values than the PWE and the HCs, while there was no difference among the groups in depression and self-esteem. Results also show higher unemployment levels and lower marriage rates for the PWE, where education levels were equal. Although the PWM had higher impact of illness values, the PWE were shown to have higher stigma, more concealment behavior, and higher traditional/spiritual healing application ratios. Also, the PWM emphasized the importance of being “able to fulfil daily living, social and work activities”, while the PWE emphasized the need for “independence” constantly. These results indicate that, although both migraine and epilepsy are CDEMs, they have different levels of impact on patients’ lives. The impacts are socially greater in epilepsy and extend beyond the neurological condition itself.

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1. Introduction

Epilepsy is a common chronic neurological disorder which is characterized by recurrent seizures. However, classifying epilepsy merely as a neurological disorder is inadequate since it is also a disorder with negative social consequences. Persons with epilepsy (PWE) usually suffer from unemployment and/or underemployment, lower marriage rates, and social discrimination.^{1–4} All these factors usually result in an impaired quality of life and low self-esteem, which is intensified by the seizures themselves,^{5,6} and sometimes even by antiepileptic drug (AED) use.^{7–9} For most PWE, a diagnosis of epilepsy is equal to stigmatization,^{10,11} in particular felt stigma,¹² which in turn results in concealing epilepsy from others and spending a great amount of energy on this concealment.^{13–15} This situation also creates a serious psychological burden and sometimes social restrictions in their lives. Additionally, many PWE suffer from depression, which also impairs quality of life and introduces additional problems.^{6,16–18} Moreover, a range

of mythological and superstitious beliefs seem to surround epilepsy in every culture,^{19,20} creating a body of unscientific and misguided attitudes. This in turn, leads to the practice of traditional and spiritual healing methods, which can be observed across a wide spectrum of cultures.^{13,21–23}

Migraine is another very common neurological disorder which is characterized by recurrent attacks of pain and associated symptoms.²⁴ Both epilepsy and migraine are neurological chronic disorders with episodic manifestations (CDEMs).²⁵ Although the duration of the symptoms varies greatly in these two disorders, individuals with either condition may have symptom free periods between attacks/seizures. In both illnesses, neurological attacks can be accompanied by headache as well as by variant gastrointestinal, autonomic and psychological features.²⁶ It is believed that both result from brain hyperexcitability.²⁷ Both are umbrella disorders, each of which constitutes a heterogeneous family of disorders. In some cases, common drugs – such as, valproic acid and topiramate – are used in the treatment of both.^{28,29} Additionally, like epilepsy, migraine can cause impaired quality of life,^{30–33} and generally has a negative impact on life.³⁴ Mood disorders, especially anxiety and depression, are also common comorbid conditions in migraine and epilepsy.^{30,35}

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Despite these similarities, however, migraine and epilepsy constitute different disorders. There are a number of previous studies in which epilepsy is compared with other chronic illnesses, such as angina pectoris, rheumatoid arthritis, asthma, chronic obstructive pulmonary disease, migraine, atopic dermatitis, cerebral palsy, and cystic fibrosis.^{36–39} However, the aim of using migraine as a second research group is to highlight the contrasts between epilepsy and another illness with very similar features. The reason for this is that observed differences in quality of life between PWE and people with other chronic illnesses with very different symptoms could be attributed to the completely different etiologies and symptoms of the disorders. By using migraine therefore, it is aimed to examine possible differences between epilepsy and a similar illness in order to eliminate confounding nature of the symptoms and etiologies. Hence, any difference observed could be directly attributed to the specific nature of epilepsy.

Therefore, the present study aimed to compare PWE and persons with migraine (PWM) in terms of health related quality of life, self-esteem, impact of illness, depression, stigma and disclosure. Other affected life domains and application of spiritual/traditional healing methods were also investigated in order to understand more about what makes epilepsy different. Based on previous studies, we expected: (1) lower health related quality of life (HRQOL) values in PWM and PWE than Control participants (CPs), and in particular that PWM would have lower HRQOL values on the subscales related with physical health, and PWE have lower values on the subscales related with mental health; (2) higher depression and stigma rates and lower self-esteem values in PWE; (3) higher impact of illness scores in PWM; (4) more application of traditional/spiritual healing methods in PWE; and (5) more concealment of the illness in PWE.

2. Methods

2.1. Participants

The epilepsy group consisted of seventy participants diagnosed with epilepsy at least for four years previously, and who experienced at least one seizure within the last two years and/or who are still on AEDs. All participants in the epilepsy group had detailed neurological and neuropsychological evaluations, and patients with below average IQs (less than 90) were not included in the study. Patients with additional serious impairments (e.g. hearing, seeing, etc.) and those with other neurological and psychiatric disorders were also excluded.

For the migraine group, 56 adults with migraine were recruited. The selection criteria were experiencing migraine attacks for an absolute minimum of four years, including at least one attack in the last three months, and continuing treatment at a headache polyclinic and as well as being on prescribed medication. Likewise, PWM with below average IQs (less than 90), with additional serious impairments, and those with other neurological and psychiatric disorders were also excluded. Since epilepsy and migraine are highly comorbid, patients who have migraine or epilepsy as a comorbid condition were excluded from the study. All the participants with migraine and epilepsy were recruited during their follow-up appointments in the neurology clinic.

A control group, consisting 45 healthy adults with no history of neurological and psychiatric disorders was included. The control participants (CPs) were matched with the epilepsy and migraine groups in terms of age, gender, and year of education as far as possible (see Table 1).

The present study was approved by the Cerrahpaşa School of Medicine, and Faculty of Ethics Committee [31.01.2006, No: 2378] at Istanbul University. Additionally, all the participants gave inform consent for their participation in the study.

Table 1

Demographic characteristics of epilepsy, migraine and control groups.

| Groups | Epilepsy (n = 70) | Migraine (n = 56) | Healthy control (n = 46) |
|----------------------------------|----------------------|----------------------|-----------------------------|
| Sex (%) * | | | |
| Female | 68.6 | 87.5 | 60.9 |
| Age (SD) * | 32.3 (10.5) | 40.5 (10.4) | 35.7 (11) |
| Year of education (SD) | 9.2 (3.9) | 9.0 (4.4) | 9.3 (4.4) |
| Marital status (%) * | | | |
| Single | 48.6 | 12.5 | 15.2 |
| Married | 42.9 | 82.1 | 73.9 |
| Divorced | 2.9 | – | 6.5 |
| Widow | 5.7 | 5.4 | 4.3 |
| Occupational status (%) * | | | |
| Employed | 47.1 | 33.9 | 71.7 |
| Unemployed | 14.3 | 5.4 | 2.2 |
| Housewife | 22.9 | 41.1 | 19.6 |
| Student | 14.3 | 5.4 | 4.3 |
| Retired | 1.4 | 4.3 | 2.2 |

* $p < 0.00$.

2.2. Instruments

2.2.1. Health related quality of life (HRQOL)

We used the Medical Outcomes study short form-36 (SF-36),⁴⁰ which consists of eight subscales to evaluate different domains of HRQOL: (1) physical functioning (PF); (2) role limitations because of physical health problems (RP); (3) bodily pain (BP); (4) social functioning (SF); (5) general mental health (psychological distress and psychological well being) (MH); (6) role limitations because of emotional problems (RE); (7) vitality (energy/fatigue) (VT); and (8) general health perception (GH). The total score varies between 0 and 100, with higher scores representing a better quality of life. Although it is a generic measure, SF-36 has been used in previous quality of life research in epilepsy.^{7,39,41–50} The validity and reliability of SF-36 for Turkish population have been tested by Demirsoy.⁵¹

2.2.2. Depression

The Beck Depression Inventory (BDI),⁵² a 21 item scale, was administered to assess the depression levels of the participants. The total score varies between 0 and 63, with higher scores indicating the severity of the depressive symptoms. In the present study, 17 was accepted as a cut off point for severe depression. The validity and reliability of the BDI for the Turkish population have been tested by Hıslı.⁵³

2.2.3. Stigma

A three item scale developed by Jacoby⁵⁴ was used. In this scale, subjects are asked to state whether, because of their epilepsy, they felt that other people are (1) uncomfortable with them, (2) treated them as inferior, and (3) preferred to avoid them. The subjects marked each item with which they agreed. The subject's overall score (0–30) is the sum of positive responses, therefore the higher the score, the greater sense of stigma. The reliability of the scale was found to be 0.72.⁵⁴

2.2.4. Impact of illness

The Perceived Impact of Epilepsy Scale, developed by Jacoby et al.⁵⁵ was administered to determine the impact of epilepsy on daily life. The scale contains both generic and epilepsy-specific items. All items cover the most important areas of everyday life, including relationships with spouse/partners, relationships with other close family members, social life/social activities, work, health, relationships with friends, feelings about self, and plans and ambitions for the future. When the scale was administered to patients with migraine, the term “migraine” replaced “epilepsy” in

the items. In this scale, higher scores indicate a greater impact of the ailment.

2.2.5. Self-esteem

In order to assess the self-esteem of the participants, the Coopersmith Self-Esteem Inventory (CSEI)-Adult version was used.⁵⁶ Participants were asked to evaluate every item either as “like me” or “not like me”. The scale consists of 25 items. The validity and reliability of the scale for the Turkish population were tested by Turan and Tufan.⁵⁷

2.2.6. Clinical/demographic questionnaire

In order to collect information about the participants' clinical and demographic characteristics different questionnaires were developed for different groups. The questionnaire for the epilepsy and migraine groups contained questions about seizure/attack frequencies, the amount of medication used, the duration of the illness, the duration of the diagnosis, and the existence of other chronic conditions. Moreover, participants were asked whether they had ever concealed their illnesses, and if so the duration of and reasons for the concealment. Additionally, participants with epilepsy and migraine were asked about any spiritual healing methods they may have tried, and their opinion of the effectiveness of these methods. Lastly, participants with epilepsy and migraine were asked to report their concerns, limitations and most affected life domains in their own words in order to determine the issues of critical importance, which could not be otherwise detected by scales with predetermined frameworks. Another reason was to provide an opportunity for participants to explain what it is like to live with these disorders. The CPs' questionnaire sought information only on demographic issues and any chronic health conditions.

Participants completed the information form first, and then the epilepsy and migraine groups received the SF-36, BDI, stigma inventory, impact of epilepsy/migraine inventory and CSEI in a randomized order, in order to avoid the order effect. The CPs did not receive the stigma and the impact of epilepsy/migraine inventories, but all other scales were administered in a randomized order. All administrations were carried out in face to face interviews by the first author.

2.3. Statistical analysis

The data were analyzed using SPSS for Windows, version 17. For two grouping variables, *t* tests for independent samples were used, while data for more than two grouping variables were analyzed by means of One-Way ANOVA. For categorical variables, Chi-Square was performed.

For the qualitative analysis of the open-ended questions first, all of the answers were transferred to Excel verbatim. Following this, open-ended answers were examined by two coders who applied content analysis to the raw data. They determined some common themes and categories then classified all answers accordingly, resolving any differences regarding the classification between themselves. Both coders had master's degrees in psychology, and were blind to the aims of the study, but not to the diagnosis of the participants.

3. Results

3.1. Demographic and clinical characteristics

No significant differences were found among the epilepsy, migraine and control groups in terms of year of education ($F < 1$). On the other hand, age ($F(2, 169) = 9.21, p < 0.00$), gender ($\chi^2(2, N = 172) = 0.291, p = 0.01$), marital status ($\chi^2(6, N = 167) = 11.09$,

Table 2

Clinical characteristics of the epilepsy and migraine groups.

| | Epilepsy group (<i>n</i> = 70) | Migraine group (<i>n</i> = 56) |
|---|--|---|
| Duration of the illness (SD) | 16.6 (10.6) | 15.8 (10.1) |
| Duration of the diagnosis* (SD) | 14.9 (11.9) | 10.0 (8.3) |
| Number of medication** (SD) | 1.6 (0.8) | 2.0 (0.9) |
| Seizure/attack frequency (per month) (%) | None: 12.9 ≤ten: 72.9 ≥ten: 13.3 | None: 0 ≤three: 37.5 ≥three: 62.5 |
| Comorbidity (%)* | | |
| Yes | 11.4 | 42.9 |
| Seizure type (%) | | |
| Generalized tonic-clonic | 45.7 | |
| Simple partial | 18.8 | – |
| Complex partial | 21.4 | |
| Absence | 2.9 | |
| Myoclony | 11.4 | |
| Intractable seizures (%) | | |
| Yes | 58.6 | – |

* $p < 0.05$.

** $p < 0.02$.

$p = 0.00$) and occupational status ($\chi^2(8, N = 172) = 2.12, p = 0.00$) were found to be significantly different among the groups (see Table 1).

Results showed that there was no significant difference between the epilepsy and migraine groups in terms of their duration of the illness, while there were significant differences between how long they had known their diagnosis ($t = 2.75, df = 124, p < 0.00$) and the amount of medication currently used ($t = -2.63, df = 124, p < 0.02$). There was also a significant difference between the epilepsy and migraine groups in terms of having a comorbidity ($\chi^2(1, 126) = 16.56, p = 0.00$). The results indicated that the PWE had known their diagnosis longer, but that the PWM used a greater amount of medication and were more likely to have a comorbidity. Additionally, the time gap between the onset of the seizures/attacks and receiving the diagnosis was only $M = 1.73(\pm 3.63)$ years for epilepsy, but $M = 5.84(\pm 6.7)$ years for migraine (see Table 2).

3.2. Health related quality of life, depression and self-esteem

Results showed that, except for role limitations because of emotional problems ($F < 1$) and general mental health ($F < 1$), significant differences were observed in all the other sub-scales of the SF-36 [physical functioning ($F(2, 169) = 11.84, p < 0.00$), role limitations because of physical health problems ($F(2, 169) = 12.72, p < 0.00$), bodily pain ($F(2, 169) = 21.54, p < 0.00$), social functioning ($F(2, 169) = 4.79, p < 0.01$), vitality ($F(2, 169) = 8.1, p < 0.00$) and general health perception ($F(2, 169) = 7.94, p < 0.00$)]. Tukey post hoc analysis revealed that, in physical functioning, role limitations because of physical health problems, bodily pain, social functioning, and vitality subscales, the migraine group was at a significant disadvantage compared to the epilepsy and control groups. Only in general health perception, CPs had higher scores than epilepsy and migraine groups (see Fig. 1).

The results showed that neither depression ($F < 1$) nor self-esteem ($F < 1$) were significantly different among the groups. When the results were investigated in terms of percentages, 30% of the PWE and 25.2% of the PWM were in serious depression, compared to only 15.1% for the CPs.

3.3. Stigma, impact of epilepsy/migraine, and disclosure of the illness

Results indicated significant differences for both stigma ($t = 2.75, df = 124, p = 0.01$) and impact ($t = 4.15, df = 124, p = 0.00$) of epilepsy/migraine, such that the PWE reported significantly higher

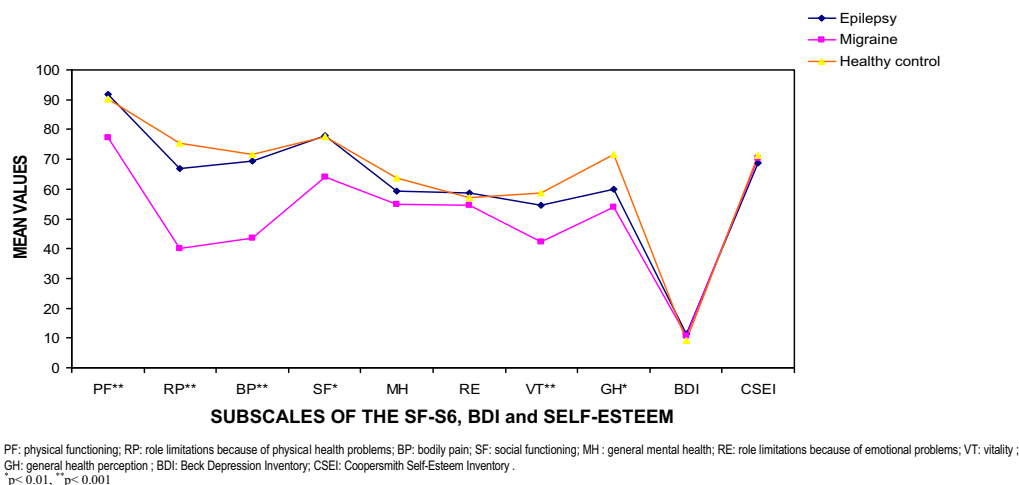


Fig. 1. Mean values of the groups in sub-scales of the quality of life, depression and self-esteem.

stigma, while the impact of the illness was greater on the PWM. Serious stigma was observed only in 14.2% of the PWE, while this ratio was only 3.6% in PWM.

There was also a significant difference in disclosure (X^2 (1, $N = 125$) = 29.67, $p = 0.00$) rates between the epilepsy and migraine groups. Results showed that none of the migraine participants concealed their condition from others, whereas regarding disclosure, 41% of the PWE had at one point concealed their epilepsy: 31% concealed it within the first few years following the diagnosis, while 69% still conceal it.

3.4. Reasons for concealment of epilepsy

In order to evaluate the reasons for the concealment of epilepsy, the responses were investigated by the two independent coders mentioned earlier. Any response citing an inner fear of stigmatization without an actual discriminatory episode was coded as “felt stigma”; but if there was real experienced discrimination caused by epilepsy, it was coded as “enacted stigma”.¹² A frequency analysis showed that 89.7% of the PWE stated felt stigma as a reason for their concealment. “I want people to evaluate me as if nothing is wrong with me, I am as healthy as they are” [F, 35], “I do not want to divulge it, I do not want to be treated as inferior” [M, 21]. Only 10.3% of the PWE concealed their epilepsy because of enacted stigma: “After people learned about my epilepsy, they acted with prejudice, so I told just my boss and close friend, no one else” [F, 28].

3.5. Application of spiritual healing methods

Among the participants with epilepsy, 55.7% had applied any spiritual healing methods, in contrast to only 12.2% of the migraine participants. The most common applications were lead casting (melting lead and pouring it into cold water over the head of a sick person in order to break an evil spell), carrying a written charm, and consulting a Hodja. The results showed that (X^2 (1, $N = 125$) = 24.47, $p = 0.00$) the PWE applied spiritual healing methods to a significantly greater extent than the PWM. However, 92% of the PWE evaluated spiritual methods as not beneficial, as did 95.2% of the migraine group. There was no difference between the PWE and the PWM in their evaluation of spiritual healing methods as non-beneficial.

3.6. Most reported concerns, affected life domains, and restrictions

For the PWE the most frequently reported concern was “having a seizure outdoors”, while for the PWM it was “being unable to

fulfil daily living activities” and “the possibility of having a migraine attack”. Other reported concerns by the PWE, according to their report frequencies, were “being alone while having a seizure”, “having an accident or dying due to a seizure”, “having a child”, “ambiguity about the future”, “AEDs”, “being a burden to others”, “negative consequences on independence”, “deterioration in mental health” and “relations with the opposite sex”. The other concerns reported by the PWM were “long term damage to health caused by migraine”, “deterioration in mental health”, “relations with the opposite sex and family”, “ambiguity about the future”, and “low performance at work”.

The most frequent responses to the question about which were the most affected life domains due to epilepsy were: “work/education/family life”, “personal independence”, “social-physical activities”, “cognitive abilities”, “psychological well being”, “romantic relations”, “physical health” and “driving”. The answers given by the PWM to the same question were: “social life/daily living activities”, “relations with the opposite sex and with family”, “psychological well being”, “work/family life”, “cognitive abilities”, and “physical health”.

To the question about the restrictions caused by epilepsy, the responses given by the PWE, in decreasing order of frequencies were: “driving”, “social-physical activities”, “lack of independence”, “avoiding activities which can trigger a seizure”, “education/work life” and “compulsory military service”. The responses of the PWM to the same question were: “avoiding activities which can trigger a migraine attack”, “social-physical activities”, and “daily living activities”.

4. Discussion

4.1. Differences in demographics and clinical characteristics

The results showed no difference among the groups in their level of education, as reported by previous studies.^{1,4,58} However, the PWE were more likely to be unmarried and unemployed when compared with the PWM and the CPs, a finding consistent with previous reports.^{1,4,59} The point to emphasize here is that the lower marriage and higher unemployment rates in the PWE were not related to the level of education, which was approximately equal across the groups. Therefore, this suggests that other possible reasons, such as felt and/or enacted stigma may be responsible.⁶⁰

When the epilepsy and migraine groups were compared in terms of their clinical characteristics, it was found that the epilepsy group had been aware of their diagnosis for longer than the migraine group. This difference is probably caused by the feeling of

urgency to consult a physician after experiencing a seizure. On the other hand, the PWM used more medication and had more comorbid conditions than the PWE.

4.2. Quality of life, depression and self-esteem

In terms of the quality of life results, contrary to expectations, the PWE only scored lower than the CPs on the general health perception subscale of the SF-36, while on the other subscales the scores of the two groups were comparable. As expected, and consistent with previous studies,^{31,32,61,62} the PWM received lower scores in physical functioning, role limitations because of physical health problems, bodily pain, social functioning and vitality subscales than the epilepsy and the CPs, showing a lower quality of life among the PWM. This finding is also in contrast to studies which showed that PWE have lower quality of life scores when compared to general reference population,^{7,41,48,49} and to a recent study,³⁶ that compared epilepsy, migraine and diabetes, finding that PWE are more likely than PWM to rate their health as only “fair” and “poor”. A small number of studies have shown that if the seizures are under control, PWE have similar quality of life values to general population.^{63–65} In the present study however, more than half of the participants had intractable seizures. The comparable scores in HRQOL scores between the epilepsy group and the CPs in the present study are reflected in previous studies. For example, in a study by Stavem et al.³⁹ PWE were compared with participants with other diseases, and were found to have higher quality of life values. The researchers suggest that PWE have better overall health perception than people with many other chronic illnesses.³⁹ As in the present study’s finding, Aldenkamp et al.⁵⁸ found that only 6% of participants with epilepsy had lower quality of life values. Additionally, previous studies from other Muslim and collectivistic countries such as Tunisia,⁴³ Jordan,⁶⁶ Bahrain, Lebanon and Qatar⁴¹ support the present study’s findings. This could be explained by the effect of Islamic religion which emphasizes acceptance of God’s will in every condition, and tends to regard attitudes which are hostile to the idea of destiny as a major act of sinfulness. Also, as stated by Kağıtçıbaşı,⁶⁷ the concept of culture of relatedness (collectivism) prominent in the aforementioned countries, refers to contexts and relational patterns characterized by relations between connected, expanding and therefore, partially overlapping selves, which have diffuse boundaries (p110).⁶⁷ Therefore, in these societies with closely knit human/family relations, the family unit could serve as a buffer to soften the negative impacts of a chronic illness, which include impacts on the patient’s quality of life. In order to clarify our understanding of the HRQOL in both Muslim and collectivistic countries, more research is needed. Another explanation, suggested by Selai et al.⁶⁸ may be that rather than considering epilepsy as part of their general well being, PWE treat it as a separate entity. A final explanation could be the generic structure of the SF-36. Since the SF-36 contains items which specifically aim to assess pain and the limitations it causes, it may be more sensitive to illnesses like migraine.

Contrary to our expectations, the present results for depression show no difference among the PWE, the PWM and the CPs. Although more than half of the participants had intractable epilepsy, only one-third of the participants with epilepsy were found to be depressed, consistent with previous studies.^{18,46,64,69,70}

Regarding self-esteem, again contrary to expectations, the PWE were no different from the PWM and the CPs. This finding is also in accordance with previous reports.^{15,71} On the other hand, there are studies that indicate that self-esteem is negatively affected by epilepsy-related variables, such as the existence of intractable seizures, side effects and the amount of AEDs.⁷² The contradictory results from different studies so far indicate that further research is

needed in particular to understand the effects of intractable seizures.

4.3. Impact of illness, stigma, and disclosure

In accordance with our expectations, the impact of migraine was found to be higher than the impact of epilepsy. Although the PWM were shown to have lower quality of life and higher impact of illness scores and there was no difference between the epilepsy and migraine groups in depression and self-esteem, stigma is more prominent in the PWE, as we expected. Therefore, stigma seems uniquely associated with epilepsy, independent of the neurological symptoms and psychological well-being. The percentage of the PWE with a high level of stigma in the present study is also consistent with previous results.^{42,54,73,74} Another interesting finding, also in line with our expectations, was that almost half the PWE have concealed/or still conceal their illness, whereas none of the PWM ever did. This result alone shows that epilepsy is a disorder with considerable negative social connotations. In the present study, among those who concealed their epilepsy at some point, only about a quarter stopped concealment within few years of following diagnosis, while most still continue to do so. Hence, rather than being just a reaction to the initial astonishment, shock and ambiguity of the diagnosis, concealment seems to relate to more serious, long term concerns and almost all the PWE stated felt stigma as a reason.

4.4. Application of spiritual treatments

A final finding which shows the unique nature of epilepsy as being more than simply a neurological disorder was the clearer tendency of the PWE compared to the PWM to resort to spiritual healing methods as expected. Despite this tendency, most participants evaluated these methods as non-beneficial. In a similar study, Small et al.⁷⁵ found that Pakistani Muslims with epilepsy living in England simultaneously seek help from physicians and from religious healers. In explanation, the researchers point to the hybrid culture that the participants were exposed to, and to the neurological and spiritual components to which epilepsy is attributed to. This explanation is also likely to be valid for Turkish individuals with epilepsy because of the influence of both Eastern and Western values.

4.5. Most reported concerns, limitations and affected life domains

In the present study the PWE and the PWM were asked to report their concerns, limitations and most affected life domains in their own words to determine critically important issues in their lives. A categorization of the answers indicated that the most reported concern for the PWE was “having a seizure outdoors” followed by “being alone during a seizure”, which are in accordance with previous findings.^{76–78} As previously highlighted,^{76,78,79} fear of seizure, and of seizure-related death can cause an impaired psycho-social adaptation to epilepsy, the higher the degree of these fears, the greater the psychopathological risk. These concerns should be treated with sufficient consideration to reduce the impact of such limitations on the lives of PWE in general. The most important concern reported by the PWM was “not fulfilling their daily/social activities” which is an expected concern since during the migraine attack most of the PWM were unable to perform daily domestic and work related activities.

As their most affected life domain, the PWE reported “Work/education/family life”. The most affected life domain reported by the PWM was “social life/daily living activities”. Lastly, both the epilepsy and migraine groups were asked to report the limitations caused by their illnesses. “Driving” was the most reported concern

by Turkish adults with epilepsy, in common with their Western counterparts.^{80–82} The most reported category by the PWM was “avoiding behaviours which can trigger a migraine attack”.

When the answers given by the PWE to the three open-ended questions were investigated, only “independence” emerged as a common category. The main reason for this is likely to be the overprotective behaviours of families toward individuals with epilepsy, starting immediately after diagnosis, which can damage the self-esteem and independence of patients.⁵ Especially in a country like Turkey with very strong family ties, this situation tends to result in a family-dependent patient. For this reason, most of the PWE were unable to travel alone or access higher education, and were therefore likely to be unemployed.

4.6. Limitations of the study

The most important limitation of the present study is the demographic differences among the three study groups, especially between the epilepsy and migraine groups in terms of their attack/seizure frequencies. Another limitation is the selection of participants from a hospital rather than the general population, since some findings indicate that, especially for migraine, such patients are more likely to have severe migraine, more frequent attacks and more comorbid illnesses (Clouse and Osterhaus, 1994, cited in Ref. 31]. Additionally, patients under the care of a neurologist in a hospital setting may be different from those without this opportunity in terms of their seizure/attack control and adjustment to their illness. Therefore, the epilepsy and migraine patients in this study may not be representative the general migraine and epilepsy population.

5. Conclusion

In contrast to many previous studies, the present study showed that the participants with a high number of intractable seizures had quality of life, psychological well being, and self-esteem values not dissimilar to those of the CPs. On the other hand, almost half of the PWE had concealed/still conceal their epilepsy. Additionally, the higher unemployment and lower marriage rates, and impaired personal independence indicate that PWE still struggle, especially with social problems. Furthermore, comparisons with the PWM indicate that the probable causes of these problems extend beyond the neurological condition itself.

Conflict of interest

The authors declare no conflict of interest. The present study was approved by the Istanbul University, Cerrahpaşa School of Medicine, Faculty of Ethics Committee [31.01.2006, No: 2378]. We also confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Acknowledgments

I would like to thank Dr. Ann Jacoby and Dr. Gus Baker, whom I see as my honorary advisors, for their valuable comments and for their permission to use Stigma and Impact of Epilepsy Scales. Also, I am deeply grateful to all of the participants for their contributions to the study without any personal benefits for themselves (N.A).

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